BEHAVIOR, SOCIAL COMPETENCE AND QUALITY OF LIFE IN HUNTINGTON'S DISEASE

Comportamento, competência social e qualidade de vida na doença de Huntington

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ABSTRACT

Purpose: to investigate the behavior, the social competence and the quality of life of subjects with Huntington Disease (HD). **Methods:** the sample was constituted of 30 participants, from 33 to 79 years old, divided in two groups: 15 participants in the experimental group (EG), who were previously diagnosed with Huntington Disease and 15 participants in the control group (CG), equally paired according to age and education. The Behavioral Inventory, constituted by the Adult Behavior Checklist and the Quality of Life Questionnaire WHOQOL – 100 were used to assess the caregivers. **Results:** the Behavioral Inventory showed statistically significant differences for the EG when compared to the CG, with high scores for internalized factors (anxiety, depression, isolation, somatic complaints), total problems and other problems as thinking, attention and hyperactivity, according to their caregivers opinion. In the Quality of Life Questionnaire the EG presented statistically significant differences when compared to the CG, in all areas (physical, psychological, level of independence, social relationships, environment and religious aspects). In most of the assessed aspects EG presented low average of quality of life, while the CG presented high average. **Conclusion:** subjects with HD present behavioral, social competence and quality of life differentiated and altered profile, according to their caregivers, when compared to CG. HD is a limiting, progressive disease that seems to be responsible for the set of behavioral, social competence and quality of life changes reported by their caregivers.

KEYWORDS: Huntington Disease; Behavior; Social Behavior; Quality of Life

INTRODUCTION

Huntington's disease - HD - (OMIM #143100; ORPHA399), described by George Huntington in 1872[1-3], is a neurodegenerative condition, with autosomal dominant inheritance, caused by an expansion of CAG repeat in the huntingtin gene, located on the short arm of chromosome 4 in the region 16.3. The diagnosis is performed by the presence of progressive motor and cognitive symptoms, positive family history and is confirmed by genetic testing[1-3]. However, Henley and colleagues (2009) showed that changes in brain volume and the neural connections may be present before the onset of symptoms[4].

The prevalence of this condition is estimated at 1 per 10,000 or 20,000 individuals, but with variations in different regions and ethnic groups[3].

The phenotype of HD is characterized by impairments in motor skills (e.g., tic movements, changes in gait, stiffness, etc.), cognitive skills (e.g., deficits in visual memory, auditory, verbal and attention), and behavioral changes, psychological and language[1-3,5]. The decline of oral language, receptive and expressive level, can be triggered by two factors: neurodegeneration and motor disorders[6,7].

Issues relating to behavioral changes described in DH seem to be related both to the progressive cognitive decline as the psychological changes, including depression, anxiety, irritability and apathy

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are the most frequent in these individuals compared with healthy individuals[8-10].

Regarding quality of life, there are reports of suicide justified by depression and physical dependence caused by the impact of symptoms on daily activities[11,12]. Therefore, the DH impairs the mental health of individuals and may be observed suffering and emotional stress among family throughout the course of the disease[13,14].

Although literature has studies on the behavioral aspects related to DH, few studies are conducted on the behavioral profile, social competence and quality of life of these individuals[8,10,12,15-17].

Therefore, this study aimed to investigate the behavior, social competence and the quality of life of individuals with Huntington's disease, according to the opinion of their caregivers.

METHODS

The study was approved by the Research Ethics Committee of UNESP - Marilia, under the protocol number 0710/2013, and participants signed the Informed Consent (IC).

The participants were 30 individuals of both genders, with age between 33 and 79 years. The individuals were divided into two subgroups: sample group (SG) consisting of 15 individuals with a diagnosis of Huntington's disease; and control group (CG), consisting of 15 i individuals without diagnosis or symptoms and negative family history for HD.

For inclusion of SG, were considered: diagnosis of Huntington's disease and signing the Informed Consent. Longer as exclusion criteria were considered: not confirmed diagnosis of HD, comorbidity with other disorders and individuals who refused to participate in the study.

Behavioral Assessment and social competence

To investigate the behavior and social competence (e.g., aggressive behavior, anxiety / depression, social problems, etc.), it was applied the Behavioral Inventory consisted of the Adult Behavior Checklist (ABCL)[18] in caregivers (i.e., family members or not) of individuals to the HD.

This inventory consists of 126 items that list a number of desirable or destructive behaviors which the applicant must select the frequency in which these behaviors occur. It was attributed to each item / issue "zero" when it is not true or does not occur; "1", if it is sometimes real or does not occur frequently; and "2", it is very true or often occurs[18].

The items presented on ABCL comprise 14 individual scales corresponding to different individual's behavior problems: (1) internalizing - anxiety, depression, anxious/depressed, isolation, somatic complaints, somatic problems, withdrawn; (2) externalizing - aggressive behavior, rule-breaking behavior, intrusive; (3) Others- antisocial personality problems, thought problems, attention/hyperactivity problems.

Evaluation of Quality of Life

The Quality of Life Questionnaire WHOQOL-100[19] lists a number of issues relating to the family or caregiver vision on quality of life and health of the individual, and for each respondent marks the frequency with which these problems occur.

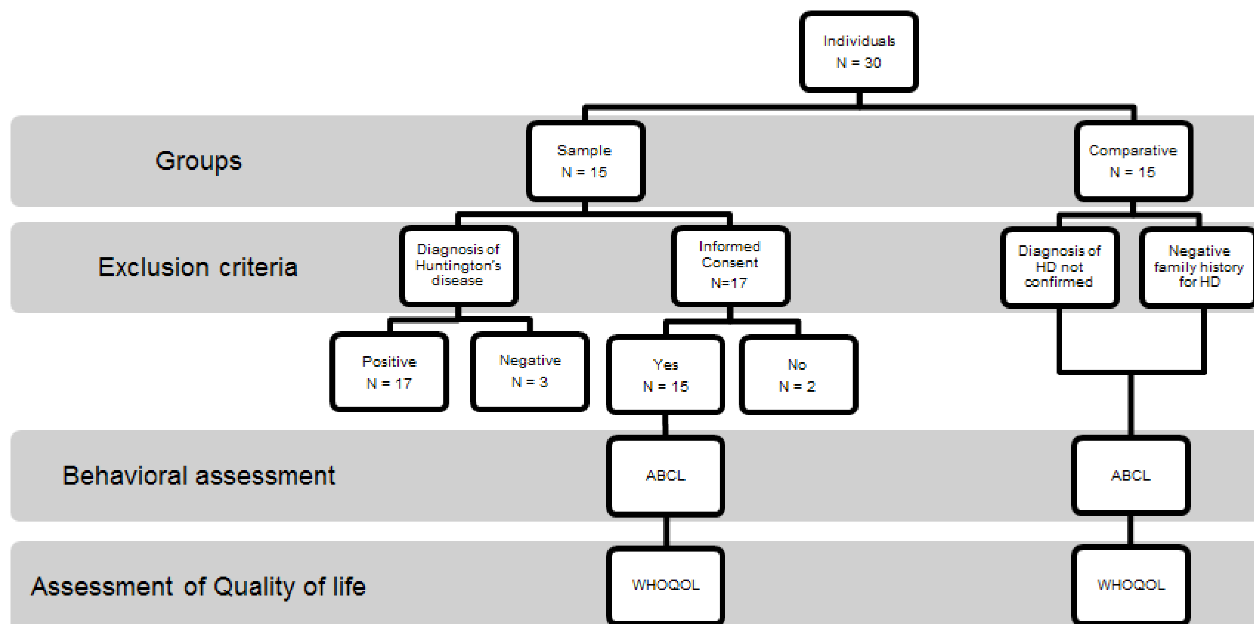
For this, the WHOQOL-100[19] evaluates six domains, consisting of 24 sub-items, as follows: (1) Domain 1 - physical, composed of sub-items "pain and discomfort", "Energy and fatigue" and "Sleep and rest"; (2) Domain 2 - psychological, consisting of sub-items "Positive feelings", "Thinking, learning, memory and concentration", "Self-esteem", "Body image and appearance" and "Negative feelings"; (3) Domain 3 - level of independence, composed of sub-items "mobility", "Activities of daily life", "drug addiction or treatment" and "Ability to work"; (4) Domain 4 - social relations "personal relations", " social support " and "sexual activity"; (5) Domain 5 - environment, consisting of the sub-items "Physical security and protection," "Home environment", "financial resources", "Health care and social: availability and quality," "opportunity to acquire new information and skills" "Participation in and opportunities for recreation / leisure", "Physical environment: pollution / noise / traffic / climate" and "Transport"; and (6) Domain 6 - spiritual aspects / religion / personal beliefs, consisting of sub-items "Spirituality / religion / personal beliefs."

Figure 1 presents the selection phase, according to criteria of inclusion and exclusion, as well as the assessment procedures used in this study.

DATA ANALYSIS

The analysis of data collected by the Behavior Inventory was performed using the Assessment Data Manager Software (ADM), which is the program developed for analysis of this procedure[20].

In addition to this analysis, the data collected by the instruments were submitted to descriptive and comparative statistical analysis using the Statistical Package for Social Sciences software (SPSS), in its version 21.0.



Caption: ABCL: Behavioral assessment questionnaire; WHOQOL: Quality of Life Questionnaire

Figure 1 – Sample selection Stages and evaluation methods

RESULTS

Behavioral Inventory of *Adult Behavior Checklist (ABCL)*

The results obtained by this behavioral Inventory *ABCL* were analyzed according to the score obtained for each of the eight scales isolated and subsequently grouped into Internalizing, Externalizing and Total Problems Scales.

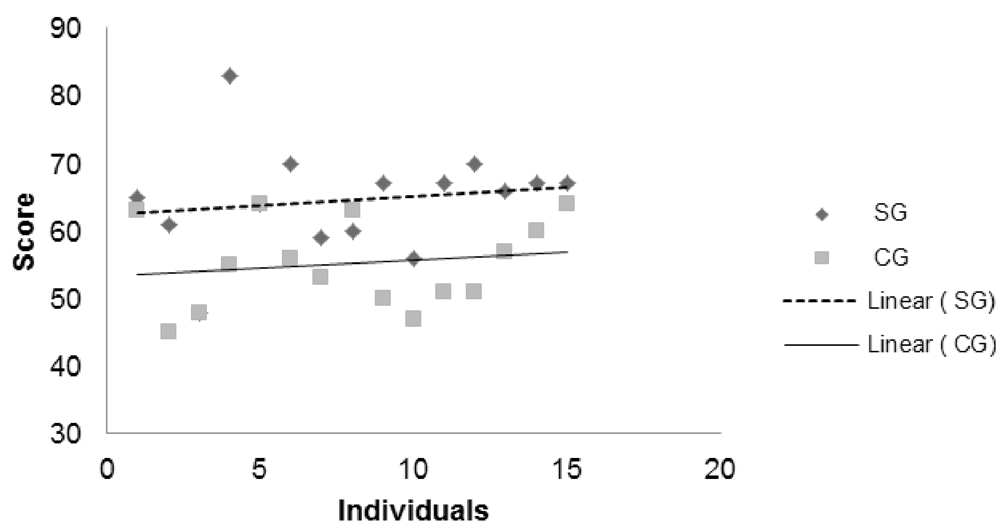
The attitudes that compose such scales are presented in Table 1 in an isolated manner, which also presents the comparison between SG and CG in all *ABCL* scales.

After analyzing the isolated behaviors, it was carried out analysis of the set of behaviors grouped to form the scales. Figure 2 demonstrates the performance profile of the individuals of the SG and CG regarding Internalizing Scale. Figure 3 shows the same profile in relation to Externalizing Scale and in Figure 4 compared to the Total Problems Scale.

TABLE 1. Comparison of results in behavioral scales ABCL in the sample and comparison groups, according to opinion of their caregivers

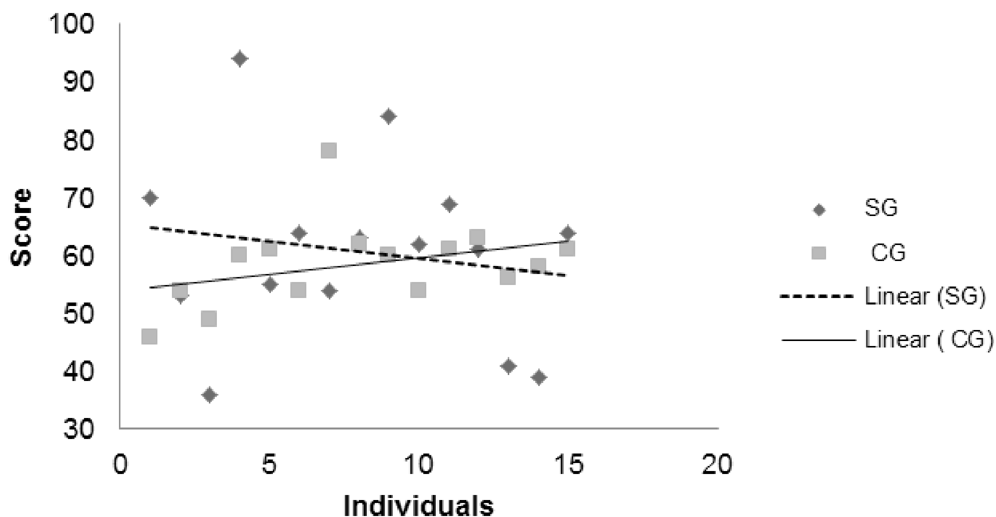
Scales		SG				CG				(p)
		Mean	SD	Min.	Max.	Mean	SD	Min.	Max.	
Internalizing Problems	Depression	66,33	6,02	53,00	74,00	55,87	6,07	50,00	66,00	0,001*
	Anxiety	61,93	6,55	50,00	70,00	60,53	6,83	50,00	70,00	0,491
	Anxious/ depressed	62,67	4,59	50,00	68,00	58,00	4,83	50,00	64,00	0,008*
	Isolation	65,13	6,88	55,00	77,00	55,67	7,97	50,00	70,00	0,002*
	Withdrawn	64,87	9,46	50,00	77,00	54,53	6,28	50,00	66,00	0,003*
	Somatic complaints	60,87	7,05	50,00	79,00	52,93	4,15	50,00	62,00	0,001*
	Somatic problems	59,07	6,50	50,00	77,00	53,27	4,25	50,00	62,00	0,008*
Externalizing Problems	Aggressive behavior	63,47	11,54	50,00	94,00	59,27	6,31	50,00	70,00	0,406
	Rule-breaking behavior	59,07	10,26	50,00	81,00	54,93	5,42	50,00	69,00	0,705
	Intrusive	56,47	9,09	50,00	78,00	57,33	5,77	51,00	73,00	0,159
Total Problems	AD/H problems	70,00	11,71	53,00	97,00	56,73	5,47	50,00	70,00	0,001*
	Thought problems	64,87	11,08	50,00	85,00	52,67	4,82	50,00	64,00	0,001*
	Antisocial personality problems	59,07	10,45	50,00	84,00	56,60	5,91	50,00	67,00	0,770
	Attention problems	70,33	10,80	54,00	94,00	55,13	5,06	50,00	63,00	0,001*
	Social	42,27	11,53	26,00	58,00	49,20	8,22	35,00	60,00	0,071
	S.U. tobacco	53,27	5,06	50,00	65,00	50,00	0,00	50,00	50,00	0,017*
	S.U. alcohol	50,00	0,00	50,00	50,00	50,60	2,32	50,00	59,00	0,317
	S.U. drugs	50,00	0,00	50,00	50,00	50,00	0,00	50,00	50,00	0,999
	Mean Substance use	52,13	3,25	50,00	59,00	50,33	1,29	50,00	55,00	0,061

Caption: SA = sample group; CG= comparative group; SD: Standard Deviation; *p-value ≤0,005: statistically significant; Min: minimum; Max: maximum; AD/H problems: Attention deficit/hyperactivity problems; S. U.: substance use.
Test: *Mann-Whitney*



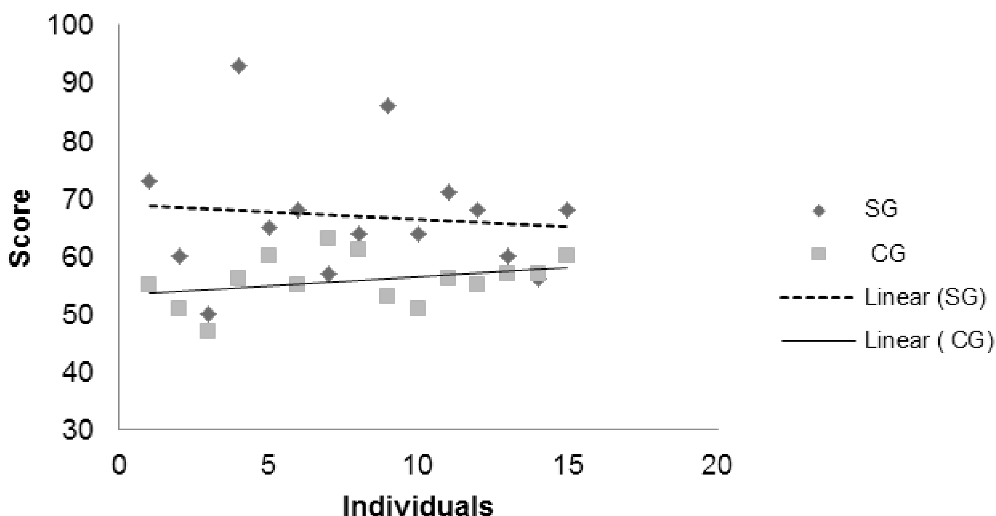
Caption: SA = sample group; CG= comparative group.

Figure 2 – Comparison of the results of ABCL between the sample group and the control group, according to the internalizing factors



Caption: SA = sample group; CG= comparative group.

Figure 3 – Comparison of the results of ABCL between the sample group and the control group, according to externalizing factors



Caption: SA = sample group; CG= comparative group.

Figure 4 – Comparison of the results of ABCL between the sample group and the control group by total problems

Figure 5 shows the change in average score of considering the age as a determining variable. It is observed that the range of CG score (47 to 63 points) has lower gap when compared with the SG (56 to 93 points). Therefore, advancing age does not seem to be decisive for issues related to behavior.

WHOQOL Questionnaire

In the replies of the caregivers to the WHOQOL-100 questionnaire it was noted that there were differences in average score of between the SG and CG groups in all domains (Figure 6).

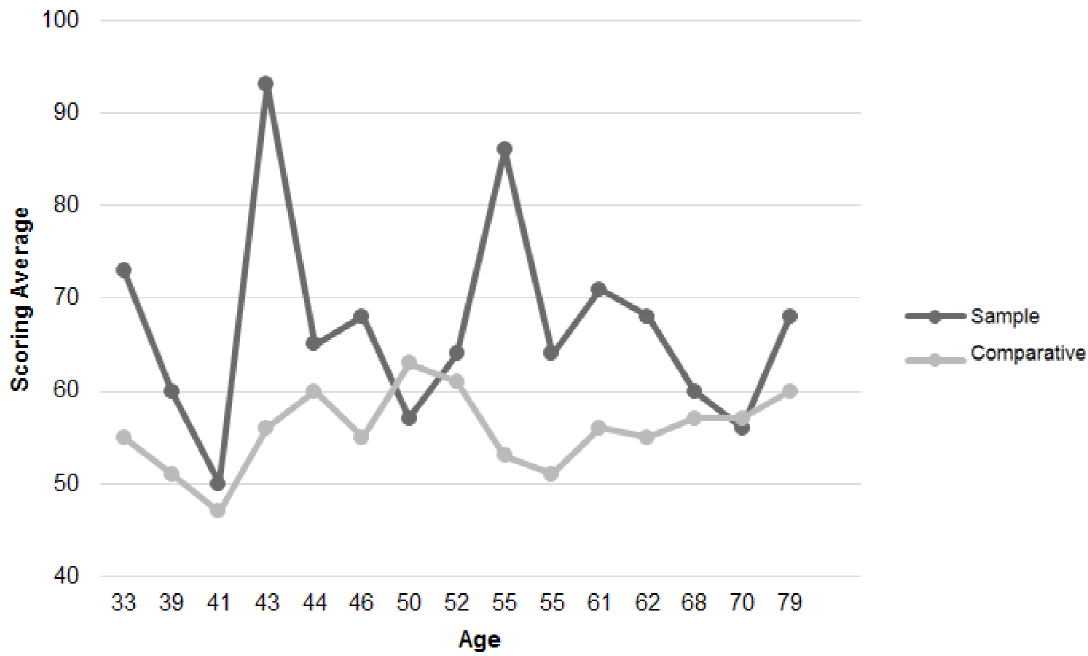
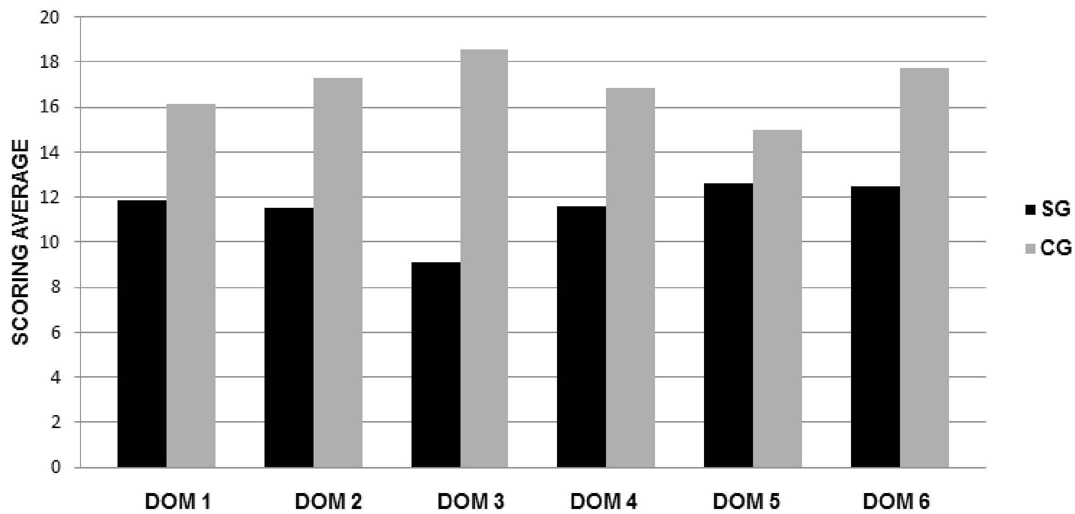


Figure 5 – Comparison of the average overall score of the sample group and control group considering the age variable in ABCL behavioral Inventory



Caption: SA = sample group; CG= comparative group; DOM 1: physical; DOM 2: psychological; DOM 3: level of independence; DOM 4: social relationships; DOM 5: environment; DOM 6: religious aspects.

Figure 6 – Scoring average distribution of the sample group and control group, according to the domains of the questionnaire of quality of life WHOQOL

Table 2 presents data comparing SG and CG for all sub classification that compose the questionnaire on quality of life, where it appears that only three sub-items had no significant difference when comparing the groups.

The average score of for the quality of life due to age was drawn, and as a result it is observed that the change in score for SG was greater than for the CG. In this regard the increase in age was not decisive for the increase in score (Figure 7).

Table 2 – Comparison of sub-items of the WHOQOL quality of life questionnaire between individuals with and without Huntington's disease, according to the opinion of their caregivers

Subitems	SG				CG				(p)
	Mean	SD	Min.	Max.	Mean	SD	Min.	Max.	
Pain and discomfort	12,53	3,70	6,00	17,00	8,13	2,23	6,00	14,00	0,002*
Energy and fatigue	11,53	2,59	8,00	16,00	16,27	1,75	12,00	18,00	0,001*
Sleep and rest	12,53	3,68	7,00	19,00	16,27	2,31	12,00	20,00	0,006*
Positive feelings	11,93	1,83	8,00	15,00	17,33	1,29	16,00	20,00	0,001*
T.L.M.C.	9,87	2,45	5,00	13,00	17,00	1,51	15,00	20,00	0,001*
Self-esteem	10,53	3,14	5,00	16,00	17,80	1,21	16,00	20,00	0,001*
Body image and appearance	12,13	4,03	6,00	19,00	17,20	1,82	14,00	20,00	0,001*
Negative feelings	11,00	2,65	6,00	17,00	7,07	1,44	5,00	10,00	0,001*
Mobility	11,87	3,46	6,00	19,00	19,47	0,92	18,00	20,00	0,001*
Activities of daily life	9,27	2,84	6,00	16,00	18,27	1,03	17,00	20,00	0,001*
M.A.T.	15,67	4,12	7,00	20,00	6,00	1,51	4,00	9,00	0,001*
Ability to work	7,00	3,14	4,00	13,00	18,47	1,60	16,00	20,00	0,001*
Personal relations	13,60	3,00	6,00	18,00	16,80	1,21	15,00	19,00	0,001*
Social support	13,13	3,76	4,00	20,00	15,73	1,22	14,00	18,00	0,010*
Sexual activity	8,00	1,81	6,00	13,00	17,93	1,53	16,00	20,00	<0,001*
Physical security	12,73	1,83	10,00	17,00	12,53	1,13	11,00	14,00	0,914
Home environment	15,00	1,89	11,00	19,00	17,20	1,86	14,00	20,00	0,006*
Financial resources	11,87	3,16	7,00	16,00	15,33	1,92	12,00	20,00	0,006*
Health care and social	13,80	3,53	6,00	20,00	14,33	1,68	12,00	17,00	0,833
O.A.I.S.	10,27	1,83	8,00	13,00	17,07	1,49	15,00	20,00	< 0,001*
P.O.R.L.	9,67	1,99	7,00	13,00	14,27	1,62	11,00	17,00	< 0,001*
Physical environment	12,73	2,46	6,00	15,00	12,27	0,96	11,00	14,00	0,202
Transport	15,00	2,42	12,00	20,00	17,07	1,67	14,00	20,00	0,015*
Spiritual aspects	12,47	3,16	7,00	17,00	17,73	1,49	15,00	20,00	< 0,001*
Quality of life	12,60	2,75	8,00	17,00	17,00	1,36	16,00	20,00	< 0,001*

Caption: SA = sample group; CG= comparative group; SD: Standard Deviation; *p-value ≤0,005: statistically significant; Min: minimum; Max: maximum;T.L.M.C.: Thinking, learning, memory and concentration; M.A.T.: Medication Addiction or treatments; O.A.I.S.: Opportunity to acquire new information and skills; P.O.R.L.: Participation in and opportunities for recreation / leisure.

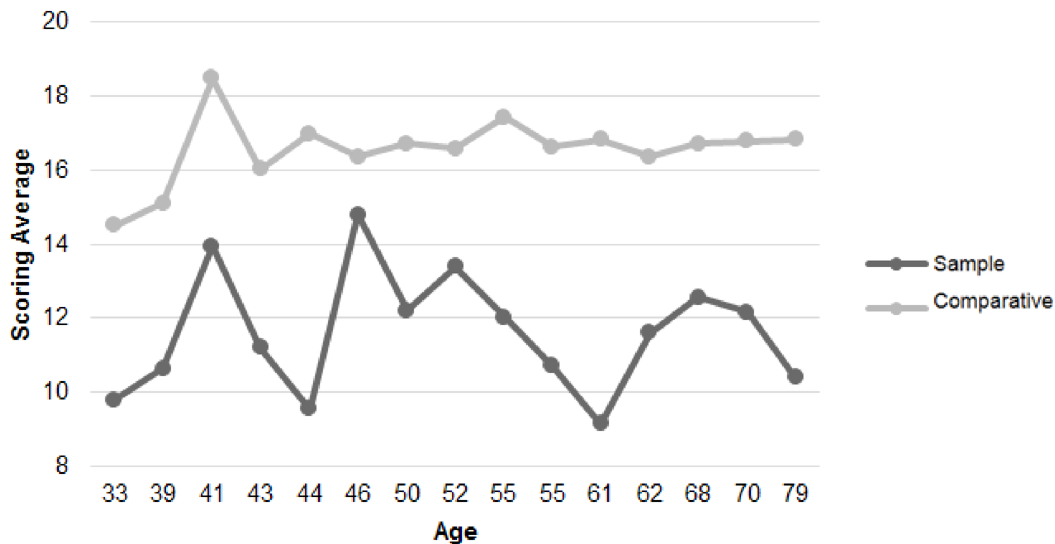


Figure 7 – Comparison of average overall score of the sample group and control group considering the age variable in the WHOQOL

DISCUSSION

Using the data obtained from the Behavioral Inventory, it was observed that the SG when compared to the CG showed statistically significant differences in internalizing factors (Table 1, Figure 2) and total problems (Table 1; Figure 4), suggesting that the behavioral profile with changes involves not only the individual but also the environment where he is inserted, consequently showing losses in his social relation[11-14].

Among the behavioral characteristics investigated, there is high incidence of social isolation, avoidance, somatic complaints, somatic problems and depressive feelings, the latter is a finding that may also be observed in other studies and identified as responsible for the high rate of suicide in individuals with HD[15,21]. Anxiety was also one of the changes often mentioned by caregivers and is pointed as a major cause of problems in interpersonal relationships of individuals with HD and their caregivers[9,15,22,23].

Behavioral changes such as aggression (attitudes of mood swings, irritability and verbal or physical attacks on other people) was mentioned by 50% of the caregivers in this study. This data can be justified, according to literature, as a neuropsychiatric symptom unrelated to cognitive or motor deficits and may have as a predictor anxiety[16, 23-25].

In relation to the data found in the WHOQOL, it is emphasized that there is no cut-off points for scores, so the higher the score the better the quality of life of individuals. According to the results, it appears that individuals with HD, when compared to healthy individuals, they had lower scores in all domains and global scope. These data are in agreement with findings of previous studies that identified in this respect, negative influences of the disease since the beginning of its manifestations, according to family / caregivers[14,17,26].

Considering the different domains of assessment of quality of life, it is emphasized that the SG had a significant gap when compared to CG, showing that the level of dependency can be seen as one of the factors that negatively impact the quality of life. The findings of this study confirm the literature findings, which register the presence of physical changes and functional impairment of the individual with HD as dependency factors, according to the progression of the disease, affecting also their quality of life. Therefore, they are responsible for overload of physical and mental work of family / caregiver[14,26].

Given the data presented, it can be suggested that HD causes significant behavioral changes in social competence and quality of life of individuals regardless of age (Figures 5 and 7), according to the caregivers. It is noteworthy that the data corroborate those described in study with symptomatic individuals and in risk of the development of the disease when it was observed that the emotional health and social participation are important factors in quality of life, mentioned even before the physical health[17].

CONCLUSION

Individuals with HD have a behavioral profile of social competence and quality of life distinguished and with more changes, according to their caregivers when compared with the control group. Huntington's disease is limiting, progressive and appears to be responsible for the set of behavioral, social and quality of life changes as reported by their caregivers. Complementary and cross-sectional studies could answer important questions about the impact of this disease, in relation to the advance of symptoms, behavioral profile, social competence and quality of life, according to the viewpoint of the individual himself with HD.

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RESUMO

Objetivo: investigar o comportamento, a competência social e a qualidade de vida de indivíduos com a Doença de Huntington (DH), segundo opinião de seus cuidadores. **Métodos:** constituíram a casuística 30 participantes, com faixa etária de 33 a 79 anos, subdivididos em dois grupos: 15 do grupo amostral (GA) diagnosticados previamente com Doença de Huntington e 15 participantes do grupo controle (GC), pareados quanto à faixa etária, gênero e classificação socioeconômica. Para avaliação destes sujeitos foram aplicados, em seus cuidadores, o Inventário Comportamental *Adult Behavior Checklist e o* Questionário de Qualidade de Vida WHOQOL-100. **Resultados:** na avaliação do comportamento e da competência social, os sujeitos do GA apresentaram diferença estatisticamente significante em relação ao GC, segundo opinião dos seus cuidadores, com escores elevados para fatores internalizantes (ansiedade, depressão, isolamento, queixas somáticas), totais de problemas e outros, como problemas do pensamento, atenção e hiperatividade. No questionário de qualidade de vida, para sujeitos com a DH também se evidenciou diferença estatisticamente significante em relação ao grupo controle, em todos os domínios (físico, psicológico, nível de independência, relações sociais, ambiente e aspectos religiosos) e na maioria dos subitens avaliados. O GA , apresentou média baixa de qualidade de vida, enquanto o GC apresentou média alta. **Conclusão:** sujeitos com DH possuem um perfil comportamental, de competência social e qualidade de vida diferenciado e com mais alterações, em relação ao GC, segundo os cuidadores . A Doença de Huntington parece ser responsável pelo conjunto de alterações comportamentais, de competência social e de qualidade de vida, relatado pelos cuidadores.

DESCRITORES: Doença de Huntington; Comportamento; Comportamento Social; Qualidade de Vida

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